# STATE OF ALASKA DEPARTMENT OF HEALTH AND SOCIAL SERVICES DIVISION OF SENIOR AND DISABILITIES SERVICES

## INCLUSIVE COMMUNITY CHOICES COUNCIL

# Meeting Minutes Friday, June 3, 2016

## **Voting Members:**

Art Delaune
Banarsi Lal
Alavini Lata
Karli Lopez
Sara Kveum
Bruce van Dusen
Rusty Best, not present
Ken Helander

Ken Helander Patricia Branson

Cindy Shults, not present

Mary Schaeffer

## **Facilitators:**

Duane Mayes, SDS Shane Spotts, HMA

#### **Guests:**

Amanda Lofgren, AMHTA
Deb Etheridge, SDS
Ulf Petersen, SDS
Jetta Whittaker, SDS
Maureen Harwood, SDS
Randall Burns, DBH, not present
Patrick Reinhart, GCDSE

#### **Advisors:**

Theresa Brisky, not present Allison Lee, not present Kim Champney, not present Tom Chard, not present

Dave Branding Marianne Mills Connie Beemer Mellisa Heflin Sandra Heffern Denise Shelton

# <u>CALL TO ORDER – 1:00 p.m.</u> WELCOME AND ROLL CALL

Roll call of voting members and advisory members was taken.

## REVIEW AND APPROVAL OF MEETING MINUTES

Duane Mayes asked for a motion to approve the minutes from the May 2016 teleconference.

## **VOTE:**

Alavini Lata **MOVED** to approve the minutes, no second. Hearing no opposition to accepting the minutes as presented, the minutes were **APPROVED**.

#### CONTINUED ELIGIBILITY AND SERVICE PACKAGE DISCUSSION

#### *Individuals with Intellectual and Developmental Disabilities*

Shane Spotts referred council members to the draft document related to the I/DD eligibility and service package. He noted that a change was made in the fourth bullet of the eligibility criteria from the previous draft, and it now contains language that a person experiences a severe, chronic disability that results in substantial functional limitations in three of the following areas of major life activity instead of two.

Shane Spotts stated that as they continue to do further analysis on the current recipients of the CDDG grant, depending on how that comes back and if the majority of the individuals would meet level of care for a 1915(c) waiver, one of the things on the table is looking at a new 1915(c) waiver for I/DD versus a 1915(i). They don't have enough data to make a decision on that yet, but they are exploring it. What a number of other states have done is they have two or multiple 1915(c)s for particular subpopulations within the I/DD population, and these services are capped. An example of one of these different types of waivers is an employment waiver that provides day habilitation, supported employment, and respite or some other limited array of services under this lower cap. It will not be the comprehensive waiver package, but if enough people from the CDDG grant meet level of care, then this is certainly an option and will be a viable alternative for individuals who don't need as much service as is available in the comprehensive (c) package.

Shane Spotts then addressed the issue that arose from the last meeting concerning cost of care attributed to some current recipients of the CDDG. He noted that the calculations were based using weights, and were not true costs of the program to the State. Duane Mayes added that after further analysis of the data, they have determined that for the 915 people that are currently on grant services, the cost is an average of about \$9,000 per person. He also relayed that part of the confusion with the numbers presented at the last meeting was also potentially a result of miscommunication between the two State grant reporting systems, GEMS and SAMS. Maureen Harwood further clarified that when they looked into the numbers, how they were applying the rates and breaking down the units made a big difference. They were able to go back through all

the data and clear that up.

Maureen Harwood then discussed the DD Registry and Review noting that when people are determined eligible for DD services, they have the right to choose whether or not to go onto the Registry for waiver services. Sometimes the grant services they receive are enough to meet peoples' needs and they choose not to go onto the Registry. Currently the Registry has 583 individuals on it with 400 or more below the age of 21; and of the 583 individuals, 161 have a score of zero. The mean score on the list is 24, with the highest being 135 and the lowest being zero.

Duane Mayes reported that because of the fiscal crisis, SDS has reduced the Registry draw from 200 people a year to 50 people a year. But because people pass away or move out of state, they do approximately 70 additional draws per year, so they will be looking at drawing approximately 120 a year.

Shane Spotts stated that right now they are trying to cross the Registry with the CDDG to determine what the need is and what the functional eligibility of people being served is to guide the discussion around (i) versus (c) and what the appropriate services will be for those individuals.

Shane directed council members back to the I/DD document and noted that it contains a list of services which are services essentially transferring over from the grant services and then applying the waiver service definitions and provider qualifications to them as the potential array of services for the (i). If they decide to go with a (c), they could get a little more creative in the service array, because the State is not obligating itself to entitlement services and it gives the State more flexibility in the service design. He also clarified for the council that the (k) option will still be going through regardless of whether the State chooses to do an (i) or a new (c).

He asked council members if the services listed below are the services they should be considering:

- Chore services
- Supported living
- Supported employment
- Day habilitation
- Respite care
- Intensive active treatment.

Duane Mayes then reviewed the definitions and services provided under each of the above categories.

Ken Helander noted that the definitions that are used are the same in each category of service recipient. He asked where the descriptions come from and whether or not they are modifiable. Shane Spotts stated that the language of the service definitions is consistent with the language that Alaska offers on various waivers, and the definitions are always modifiable within the guidelines of CMS.

Alavini Lata stated that his major concern with the definitions is he wants to make sure it's uniformed across other services because it would be difficult to qualify individuals for eligibility if they vary. Shane Spotts added that these service definitions are only for the I/DD population.

Sandra Heffern asked if all the CDDG recipients are on the Registry. Maureen Harwood stated that she can look up how many people on the CDDG are on the Registry, but that number fluctuates. Again, some people have their needs met on the grant and choose not to go on the Registry. Deb Etheridge noted that some people on the CDDG may also not be Medicaid eligible.

Sandra Heffern also asked for clarification on the supported living definition on the I/DD document and how it appears to be only focused on assisted living homes and does not take into account the variety of other living situations for people receiving services. Shane Spotts noted that that is an oversight, and he will make modifications to this.

Denise Shelton stated that she is supportive of the additional (c) waiver options. She also liked that this seems to get people into service at a lower tier with the flexibility to move up into more comprehensive services as they age or their circumstances change.

# Alzheimer's Disease and Related Dementia (ADRD)

Shane Spotts directed council members to the draft document relating to the eligibility and service package targeted for the ADRD population and reviewed for them as follows:

Dementia is a loss of cognitive abilities in two or more areas such as memory, language, visual and spatial abilities, or judgment, severe enough to interfere with daily life. There are different types of dementia, because the root causes of the symptoms are different. Alzheimer's disease is the most common form of dementia.

Individuals meeting the criteria of this 1915(i) target group have a severe, chronic disability that:

- is attributable to ADRD;
- is manifested after the individual attains age 22;
- results in the individual, who may live alone or will live alone or be homeless, having significant difficulty with memory, using information, daily decision making, or behavioral needs that require intervention to ensure the individual does not wander, and does not put themselves or their surroundings in danger.

These individuals experience substantial functional limitations in at least three of the following areas of major life activity as a result of the loss of cognitive abilities:

- self-care
- receptive and expressive language;
- learning;
- mobility;
- self-direction;

capacity for independent living;

and a need for a combination and sequence of special, interdisciplinary, or generic assistance, supports or other services that are of lifelong or extended duration and are individually planned and coordinated.

Ken Helander commented that the third bullet about the individual who may live alone, will live alone, or may be homeless does not take into account people that live with family or who may be in a couple where one spouse is a caregiver to another, or a child living with an aged parent, or even living with a neighbor or friend. Shane Spotts stated that this has been a point of contention throughout the development of this. He stated that this is an attempt to hone in on the people who have the greatest needs or who may not have natural supports in place and are most at risk. Ken Helander continued on by stating that if there is an elderly couple and one of them has ADRD, their needs are extraordinary and this language disregards the role of the caregiver and the need for support of the caregiver. The caregiver's capacity to support the individual is a part of the consideration of supports that are provided because what is going to keep the person independent is keeping that caregiver functional and keep them from burning out. Shane Spotts stated that they need to think about a way they can put in some type of risk criteria so that can be defined, but there has to also be a threshold of need.

Ken Helander also asked that they revisit the language in their third bullet that talks about ensuring the individual and surroundings are safe to make it not so negative and that it reflects that the outcome they are looking for is safety, not preventing danger. He also suggested including verbiage regarding maintenance of health because it's not just wandering that is a problem. He suggested the following rewording:

...having significant difficulty with memory, using information, daily decision making, or exercising judgment that requires intervention to maintain health and ensure the individual and surroundings are safe.

Pat Branson agreed with Ken Helander's statements and added that 50 percent of the people they serve with ADRD are living with a friend, spouse, et cetera. She also agreed with rewording the third bullet point.

Pat Branson commented that she was unclear about the third bullet point of "learning" under functional limitations. Shane Spotts noted that these were taken from the federal criteria for nursing facilities for various levels of care.

Pat Branson also noted that the word "severe" in the above mentioned description is not clear to her in that she thinks the word severe is subjective and can become debatable when determining eligibility. Shane Spotts stated that this will be defined by the assessment tool and will not be subjective.

Sandra Heffern asked if the same kind of analysis was done for this population as was done for the I/DD population in terms of individuals being served on the senior grants to get a good feel for the types of services they are currently receiving or might need in the future. Deb Etheridge

stated that they do not collect the level of data for the senior grant program that they do for the I/DD CDDG; however, they do get diagnosis information associated with the specific programs they are looking at refinancing. For the senior and community-based grants, they will only refinance a relatively small portion of those grants, and they are assuming a smaller number would move from the senior grants into the (i) option. Sandra asked if they could consider another (c) service category for this small number of seniors. Deb Etheridge stated that she doesn't believe these individuals would meet a nursing facility level of care and instead would meet a lower level of care in an (i) option.

Shane Spotts stated that although it will not meet the needs of all Alaskans with an ADRD diagnosis, this is just a starting point for this program for the State during these tight fiscal times. It is something that can be built upon rather than trying to retract a program once it has been put into place, or have the legislature react negatively to it because it opened the floodgates.

Pat Branson agreed with the statement that it is easier to build on this program than to try to take away a program, all the while being fiscally responsible. Ken Helander commented that he understands the need to be fiscally responsible, but he reacted to the irony of having heard the very same words 30 years ago that the State can't afford it and doesn't want to open the floodgates by changing the definitions of who is eligible. He noted that 30 years ago there was a lot of money.

Denise Shelton stated that a huge population of ADRD is families supporting family in Alaska. The only people that seem to get help are the people that have something bad happen to them that puts them into an assisted living situation until they get better; and then once they heal and no longer have a physical need, they no longer qualify for waiver services and they are back in the family home with little to no supports. She sees a real need out there. Duane Mayes stated that this is still in draft form and is a work in progress.

Denise Shelton suggested adding a piece where Adult Protective Services is involved because they may have had numerous contacts with this individual for a variety of reasons.

Amanda Lofgren suggested a possible solution or strategy in the third bulleted item to put something in along the lines of a caregiver whose health and safety is at risk due to burnout, or something to that effect. She also stated that there have been past conversations relating to caregiver assessments, and she asked if the interRAI has a caregiver addendum. She stated they could create a threshold or criteria for caregiver burnout. Shane Spotts stated that they will look into that.

#### OTHER INFORMATION FOR THE GOOD OF THE ORDER

Denise Shelton asked if care coordination or case management has been discussed or considered within these service options. Duane Mayes said yes, how they define that it is a consideration, and they will circle around back to it.

Duane Mayes asked council members and advisors to further review the ADRD and SMI draft documents and make comments to send to Ulf Petersen. Shane Spotts requested that comments

be made by the end of next week. He will make himself available to any member of the council that has questions or needs clarification relating to these documents.

Duane Mayes stated that as the State continues to have planning meetings with HMA, they will generate draft information and send it out to council members and advisors for their review and comment. As soon as council members receive any information, they should review it and comment back by the deadline given.

Mary Schaeffer asked that for the face-to-face meeting, they be presented the old regulations that are in use right now plus the changes that are being made so they can have a really good picture of where they are really making changes.

## **ADJOURN**

Hearing no objections, the meeting adjourned at 3:02 p.m.